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The "Cinderella Syndrome": A narrative study of social curfews and lifestyle restrictions in juvenile myoclonic epilepsy

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ABSTRACT

Several factors are thought to contribute to inadequate seizure control in patients with juvenile myoclonic epilepsy (JME), including drug resistance, neuropsychiatric comorbidity, and poor lifestyle choices. Recent evidence supports the existence of frontal lobe microstructural deficits and behavioral changes that may contribute to poor seizure control in a minority of patients. Counseling patients on the importance of adequate sleep hygiene and alcohol restriction is an important part of the management strategy for patients with JME. However, information is lacking on how these lifestyle restrictions impact on patients with JME. We conducted a qualitative descriptive analysis of the social impact of JME on 12 patients, from their own perspective. We identified four prominent themes: the importance of alcohol use as a social "norm", how JME affected relationships, decision making (risk versus consequences), and knowledge imparting control. Given that these restrictions were interpreted by patients as social "curfews", we suggest that the term "Cinderella Syndrome" encapsulates the perceived imperative to be home before midnight. Our findings underscore the importance for clinicians to recognize that in counseling patients with JME about lifestyle adjustments, there may be a significant social consequence unique to this patient group.

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1. Introduction

Juvenile myoclonic epilepsy (JME) is a primarily generalized epilepsy that manifests typically in adolescence or young adulthood [1–4]. For the majority of patients with JME, there is an excellent response to medication therapy, with seizures in 85% of patients successfully controlled with appropriate antiepileptic medication and lifestyle adjustments [5–8]. However, several factors contribute to poor seizure control in the remaining 15% of patients, including drug resistance, psychiatric comorbidity, and what has been termed as an "abnormal" lifestyle [5]. Indeed, a specific behavioral profile was highlighted in the seminal article on JME [9]. Recent research has highlighted deficits in frontal lobe function [10,11] and social cognition [12] in patients with JME. Several lifestyle factors are known to provoke seizures in JME, in particular sleep deprivation and excess alcohol [5]. Sleep deprivation is reported as a trigger in up to 89% of JME-related seizures, and a pathognomonic feature is "chronodependency" of myoclonic jerks [13]. As is the case with epilepsy in general, a diagnosis of JME is known to carry with it considerable psychological burden, in part on account of its unpredictable nature, associated stigma, and its association with low self-esteem, anxiety, and depression [14]. The teenage years are known to be a critical period for the development of self-esteem and identity formation. The emergence of risk taking behavior [15,16] contributes to the teenage years being a particularly challenging period in which to develop a chronic illness. For many teenagers, social interaction may involve late nights out or a sleep-over with friends. For patients with JME, however, a lifestyle which involves sleep deprivation and fatigue, coupled with excessive alcohol intake, is a powerful precipitant of seizures [16]. Avoidance of sleep deprivation, therefore, is a major lifestyle adjustment necessary to reduce the risk of seizures. A bit like Cinderella, who must leave the Ball and be home by midnight, an adolescent's enjoyment may be restricted by such a 'curfew'.

While several studies have confirmed that adolescents with epilepsy have a poorer quality of life compared to other chronic conditions [14,17–19], quality-of-life studies in patients with JME are few [20,21]. Knowledge regarding the impact of lifestyle restrictions specifically as it affects adolescents is limited. It has been emphasized that JME provides a good example of where listening to patients can provide novel insights [22]. We therefore wished to explore the potential social impact of living with a diagnosis of JME from a young adult perspective, using a qualitative descriptive approach. Specific objectives of this study included an exploration of the patient's view of having a diagnosis of JME in terms of its impact on relationships, ascertainment of a patient's

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awareness of known seizure triggers, and the potential impact of possible restrictions on their lifestyle choices.

2. Methods

2.1. Patient population and study design

We used a qualitative descriptive research design, using purposeful sampling of a cohort of patients with JME attending a specialist epilepsy clinic at University Hospital Galway, Ireland. The research project was approved by the Research Ethics Committee of Galway University Hospitals. Patients were recruited between January and April 2013 and invited to participate in a semistructured interview conducted by one of the authors (TL). Inclusion criteria included patients aged between 18 and 27 years, with an established diagnosis of JME (an age-related primarily generalized epilepsy associated with myoclonic jerks on awakening, with characteristic electroencephalographic (EEG) abnormalities [3,4]). All patients were diagnosed and being treated by neurologists with subspecialty expertise in epilepsy and who contributed to this study (TC, MJH). As part of routine clinical care, all patients attending the epilepsy clinic received regular counseling regarding the importance of lifestyle adjustments as part of seizure control. Patients are provided with written material and directed to a website (www.epilepsy.ie) for further information.

Patients were excluded if the diagnosis was unclear or they had significant neurological, psychiatric, or medical comorbidity or significant learning disability. Patients gave written informed consent to participate in the recorded interview.

2.2. Data analysis and outcomes

Following a pilot study to establish the reliability of the interview process, data were gathered using a semistructured interview (Table 1), and emergent themes were identified. Audio recording was transcribed verbatim onto a database and anonymized. Initial data were generated into ideas for formal coding into meaningful thematic groups, according to the method of Braun and Clarke [23]. Thereafter the candidate themes were refined by rereading all the coded data extracts for each theme to ensure that the candidate themes sufficiently captured the coded extracts and refine the thematic map. Following completion of thematic analysis, a final report was generated for each patient.

Table 1
Semistructured questionnaire.

Question 1
"How did you feel when you were first diagnosed with epilepsy?"
Question 2
"Did your diagnosis of epilepsy have any effect on your relationships with friends or making new friends." (Prompt: "In what way?").
Question 3
"What about relationships with your family?" (Prompt: "In what way?").
Question 4
"Since you were diagnosed, do you think epilepsy has affected your day to day life (e.g., social life, family life, sports, work)?" (Prompt: "In what way?").
Question 5
"Lack of sleep and alcohol use is thought to be major triggers in provoking seizures?" "Has this ever happened to you?"
Question 6
"Do you feel avoiding these trigger factors restricted you in every-day living?" (Prompt: "In what way?")
Question 7
"Are/were there any social occasions or outings that may have been restricted due to your epilepsy (i.e., graduation parties, concerts, sleepovers/camping)?"
Question 8
"Is there anything that you would like to add in relation to living with epilepsy?"

3. Results

3.1. Demographics

Eighteen patients were identified who fulfilled the inclusion criteria, twelve of whom participated in the study. All patients had a clear history of myoclonic jerks on awakening, as well as generalized tonic–clonic seizures. Eleven of the twelve patients had at least one interictal EEG with epileptiform discharges typical of JME. One patient had a normal EEG, recorded while on treatment. Six patients declined to participate. Age of the participants ranged from eighteen to twenty-seven years, and age at diagnosis ranged from twelve to twenty years. Seven participants were female. Four patients were attending college; one had completed high school. Five patients were in full time employment, and two were unemployed at the time of interview. All patients admitted to regular alcohol consumption to varying degrees. Six patients were driving. All patients reported good adherence to anticonvulsant medication. Ten patients were taking monotherapy: sodium valproate (5), levetiracetam (2), lamotrigine (2), and topiramate (1). One female patient was taking a combination of clonazepam and lacosamide, and one patient was taking a combination of sodium valproate and lacosamide. All but one of the participants were seizure-free in the six months prior to interview; one patient had a convulsion secondary to postpartum sleep deprivation.

3.2. Thematic analysis

Four main themes emerged from the qualitative analysis which we have categorized as follows: (i) alcohol — the social "norm", (ii) relationships with others, (iii) choice versus consequences, and (iv) knowledge equals control. Table 2 includes some representative quotations from participants, relating to each theme.

3.2.1. Alcohol — the social "norm"

Alcohol consumption emerged as a strong theme, having a significant social impact in this patient group. Thirty-three percent of the participants reported this issue early in the interview prior to direct questioning regarding their views about alcohol in relation to precipitating factors and seizures. Abstaining from alcohol appeared to be more problematic for participants attending college. Two subthemes relating to alcohol consumption emerged. Firstly, participants described their social environment revolving heavily around alcohol consumption: "*Everything in Ireland is built around alcohol*". Secondly, patients referred to the impact of abstaining from drinking alcohol in this social environment: *"I used to think why should this [abstaining from alcohol] restrict…Why should I let it stop me from doing the things I want to do"*. Participants also reported difficulties in socializing when they abstained from alcohol: *"It's not the same… [in a night club]… when you're stone cold sober"* (Table 2). Feelings of isolation and being different were noted following abstinence from alcohol.

3.2.2. Relationships with others

Relationships featured strongly throughout the interviews, with early diagnosis of JME prior to high school felt to be advantageous when forming new friendships. Overall, most participants reported having positive experiences relating to relationships with family, partners, and friends. Notably, many participants reported the importance of a small close-knit circle of friends: *"I think overall generally the family did come a bit closer together. I know everyone is looking out over me"*. Eighty-five percent of participants who were in a relationship (6 of 7 participants) felt particularly supported when socializing with their partners. One participant equated feelings of being safe in their presence (Table 2). The majority of negative comments expressed by participants related to feelings of over protection: "*…. My whole family, like I have four sisters and two brothers… so they're all giving out to me when I go out*". One participant experienced negative perceptions of her

Table 2
Representative participant quotations from identified themes.

Alcohol — the social norm
- *"In Ireland everything is built around drink. It's a fact; everything around Ireland is built around alcohol. It's a terrible thing to say but it's a fact. If you weren't drinking you might as well stay at home."*
- *"The only thing that I missed was the social aspect of going out to a nightclub. Now I have been to nightclubs since but it is not quite the same in a nightclub when everyone else is falling around the place and you are stone cold sober."*

Relationships with others
- *"I have never gone out with a friend that didn't know I had it (epilepsy) in my social life."*
- *"I have just started going out with a fella three weeks ago and I wouldn't have dared to do it beforehand and that was only cause a lot of my friends were very supportive saying 'c'mon you can do it' and so I did."*

Choice versus consequences
- *"Cause it will be like everyone is having more fun than me, and if I were to have a few drinks should I have the seizure the next day…. Cause I know there is consequences like, so that's the choice I have to make…whether I am willing to drink and have fits the next day and something serious happens or not."*
- *"With the midwifery as well, I was saying I would love to do that and then saying, what if I make a mistake! I do night duty and I have a jerk, cause I still get those and drop a child or something like…its always kind of there, the fore front of your mind."*
- *"There were trips to Delphi [Adventure sports Park], I remember, em… I didn't go cause I knew would not get enough sleep."*
- *"I was living at home and couldn't go anywhere, no car. Nothing to look forward to for a while you know. I felt like I was 12 or 13 again."*
- *"I didn't go out as much, I didn't want to push it too far like. Something did happen then you would regret it all. If something should happen you would undo it all especially after a year when I got my licence back. It's all an incentive of like maybe I will take it a bit easy… em I'm not gonna undo everything that I have done already."*
- *"I didn't have a full on seizure until I was 21 and when I got the big seizure that frightened me. We were in town and we were in a night club then we went home, we went home early. My mouth was busted, I smashed my face off the radiator. I destroyed my face, I was in hospital for three days. I didn't drink for a year and half 'cause it frightened me."*
- *"I know when I was younger I used to go out and I used to drink and I used to have seizures cause I used to think why should this restrict me like. Why should I let it stop me from doing the things I want to do. But like now it's going to a stage where all I want is to be seizure free."*

Knowledge equals control
- *"My first disco was when I was 13 and the epilepsy was fairly new to us and there were disco lights and we were told there was lots of different types of epilepsy one that is photosensitive, so we were unaware of this cause I hadn't, we weren't sure of what type I had. So I was at the age where I was just you know going into my social life, you know so that was hard at first cause you know because it was new. My parents wouldn't let me out on my own."*
- *"So of course like when I was diagnosed like everyone was kinda like, can't be doing this, you can't be doing that. For a while it was like you can't be going out, you can't be staying out late! So you know once I kinda took control of it myself then you know after a year or so I came back to my own, like everything else you learn to live with it like."*
- *"They would (family) tell me to be careful with this, that and the other would get annoying after a while because I know I did my own research on it so I know myself. Cause there are limits you know my neurologist said to me."*

epilepsy voiced by her partner: *"First time I told a guy I was going out with at the time he started treating me differently, he only knew one person [with epilepsy] and they were in a wheelchair and he thought of disability…"*.

3.2.3. Choice versus consequences

All of the participants in the study were aware of the major seizure triggers in relation to their condition: "*…so that's the choice I have to make…whether I am willing to drink and have fits the next day and something serious happens, or not"*. Having to avoid these triggers to ensure seizure control resulted in missing out on social events. Four out of the seven female participants avoided sleepovers, with three out of four stating that their first seizure happened during a sleepover: *"There were trips… I didn't go, 'cause I knew I would not get enough sleep"*. Moreover, despite being seizure-free, participants remained concerned over seizure recurrence: *"If something should happen you would undo it all especially after a year when I got my licence back. It's all an incentive…"*. Fear of sleep deprivation also featured in career prospects and choices. Two participants highlighted fears of pursuing careers that may involve shift work (Table 2).

Adherence with medication was not specifically discussed at the interview; however, two female participants spontaneously brought up weight gain due to the usage of valproate.

The importance of driving and socializing was a recurrent theme throughout the interviews, particularly among the male participants. Sixty percent of male participants spontaneously discussed this topic early in their interviews. They equated the loss or potential loss of their driving license to lack of freedom, lack of spontaneity, and restricted lifestyle. Retaining their driving license promoted compliance with both medication and lifestyle in this group.

3.2.4. Knowledge equals control

Education and increased knowledge was reported by participants to have a positive impact on their quality of life and, in turn, reduced overprotection in parents: "*For a while it was like "you can't be going out", "you can't be staying out late"! So you know, once I kinda took control of it myself then after a year or so I came back to my own; like everything else, you learn to live with it"*. Disclosure and education involving seizure management to close friends was also positive as it promoted confidence and reduction in social exclusion (Table 2). Lack of education regarding diagnosis and lifestyle impacted negatively on various different aspects of participant's lives ranging from fear of disco lights when socializing to career opportunities and rights.

4. Discussion

This study explores, using qualitative research methodology, the social impact of living with JME from a young adult's perspective. To our knowledge, this is the first study to specifically address the social impact of lifestyle modification requirements in patients with JME. We have used the term "Cinderella Syndrome" in reference to the social curfew that such lifestyle restrictions impose on patients with JME in order to remain seizure-free. We identified four main themes, revolving around alcohol use, relationships, decision-making, and patient understanding of their condition.

Alcohol emerged as a strong theme regarding the social impact of JME in this patient group. Our study is based in Ireland where there is increasing concern that alcohol, "our favorite drug", plays a significant role in the culture and society [24]. All participants in our study consumed alcohol regularly, and several reiterated that drinking alcohol was part of the 'social norm' for their age group. Furthermore, abstaining from alcohol contributed to feelings of exclusion. Recent evidence supports a degree of frontal lobe dysfunction in patients with JME [10], as well as a tendency to risk-taking behavior [16], although Wandschneider et al. [16] only reported behavioral abnormalities in those patients with poorly controlled seizures. Moreover, patterns of cognitive deficits in patients with JME have been inconsistent among neuropsychological studies [22].

Although participants in our study were aware of factors associated with seizure provocation, the majority reported anxiety in managing their lifestyle. This is consistent with a previous study which found that despite good seizure control, participants remained concerned about seizure recurrence [25].

Participants in our study reported that compliance with lifestyle restrictions often resulted in missing out on social bonding with their peers. Our findings are consistent with studies among unselected patient cohorts addressing the social impact of epilepsy [26–28].

The implications of epilepsy and driving were noted repeatedly in our interviews, particularly with the male participants, who equated the loss or potential loss of driving to lack of freedom. These findings are consistent with previous studies [29–31].

A third theme that emerged from our study concerned the dynamics of relationships between participants and their social support network. Overall most participants reported having positive experiences relating to relationships with family, partners and friends. This is in contrast to a recent study [32] reporting that participants expressed reluctance to befriend a peer with epilepsy more than any other chronic condition. Overprotection is a common complaint reported by adolescents with chronic disease [32,33], and this was echoed in our cohort. Participants reported that overprotection by parents was a constant reminder of having epilepsy. However they also reported appreciation of family support. Disclosure of epilepsy by participants to friends was described as complex involving both timing and skill. This complexity of disclosure to peers is reflected in other qualitative studies [34,35]. Our findings therefore contrast with a prior study which found that adolescents with epilepsy rarely discussed their disorder with friends, compared to other chronic disorders [34].

Although participants were not asked directly about personal relationships in their interviews, seven discussed their partners, stating they were very supportive. This contrasts with earlier studies where few adolescents stated that they would date a person with epilepsy [29]. We did not encounter frequent reports of misconceptions regarding epilepsy among our cohort, in contrast to prior studies [35].

The final theme emerging from our study related to the importance of knowledge and education in the setting of JME. Participants reported reduced anxiety and stigma with increased knowledge and education. One issue related to information on diagnosis being given primarily to a participant's parents during the consultation, during which he felt excluded. This concern was also highlighted in other studies [36]. Education of friends regarding epilepsy and management of seizures was found to be very positive with this participant group as it gave reassurance to friends and reduced the risk of exclusion when socializing. The study of McEwan et al. [36] reported similar findings, where participants stated that their friends were interested in understanding the condition and especially what to do in the event of a seizure.

Participants also expressed concerns relating to potential future obstacles, for example pregnancy and employment. Admi and Shaham [28] reported similar findings relating to information gathering in their older participants. They found that younger participants gathered information relating to the here and now whereas older participants managed information oriented to the future. Some participants voiced concerns of perceived “felt stigma” where they felt that they would be discriminated against when applying for future employment or anticipated problems and delayed disclosure regarding their condition until they were established in their jobs. Other participants experienced “enacted stigma” relating to previous employment and continued to conceal their condition in current employment resulting to increased stress and anxiety. Concealment is often an immediate response for people with epilepsy to combat such fears [37].

Our study has several limitations. The small sample size and single site from the west of Ireland limit generalization of our findings. Six of the initial eighteen patients identified declined to participate in the study. Furthermore, the qualitative nature of the study necessarily carries with it some risk of bias, particularly in the interpretation of the concepts and themes generated in the interviews. Nonetheless, thematic analysis is now well established as a valid and meaningful technique in qualitative research [38]. Although the number of participants in this study was small, we believe important insights were gained into this complex area. In addition, our study did not take into account the possibility of some participants exhibiting some psychopathologic traits that are well described in a minority of patients with JME [10]. However it is worth emphasizing that the majority of patients with JME do not exhibit significant neuropsychologic deficits [22], and we feel that this is unlikely to have been a significant factor in our study. The implications for clinical practice therefore can be directly related to the findings of this study. Increased awareness, education, and a deeper understanding of the management of this condition should be recommended to young adults with epilepsy, their families, friends, and healthcare professionals. Healthcare professionals, in particular, require a deeper awareness of the potential social impact of lifestyle adherence for the young adult with JME. They also need to be encouraged to develop empathic listening skills when discussing the complexities of managing this chronic condition; this should incorporate the importance of age-specific information. Moreover, our study highlights the importance of disclosure of a diagnosis of JME by patients to close friends.

5. Conclusion

The findings of this study illustrate young adults' perspectives of the potential social impact of lifestyle restrictions in the management of JME. We feel that the application of the term “Cinderella Syndrome” captures some of the difficulties encountered by adolescents with JME.

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Conflict of Interest

The authors report no conflict of interest relating to this study.

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